

Persons with acquired profound hearing loss (APHL): how do they and their families adapt to the challenge?

Hallam, Richard; Ashton, Paul; Sherbourne, Katerina; Gailey, Lorraine

Postprint / Postprint

Zeitschriftenartikel / journal article

Zur Verfügung gestellt in Kooperation mit / provided in cooperation with:

www.peerproject.eu

Empfohlene Zitierung / Suggested Citation:

Hallam, R., Ashton, P., Sherbourne, K., & Gailey, L. (2008). Persons with acquired profound hearing loss (APHL): how do they and their families adapt to the challenge? *Health*, 12(3), 369-388. <https://doi.org/10.1177/1363459308090054>

Nutzungsbedingungen:

Dieser Text wird unter dem "PEER Licence Agreement zur Verfügung" gestellt. Nähere Auskünfte zum PEER-Projekt finden Sie hier: <http://www.peerproject.eu>. Gewährt wird ein nicht exklusives, nicht übertragbares, persönliches und beschränktes Recht auf Nutzung dieses Dokuments. Dieses Dokument ist ausschließlich für den persönlichen, nicht-kommerziellen Gebrauch bestimmt. Auf sämtlichen Kopien dieses Dokuments müssen alle Urheberrechtshinweise und sonstigen Hinweise auf gesetzlichen Schutz beibehalten werden. Sie dürfen dieses Dokument nicht in irgendeiner Weise abändern, noch dürfen Sie dieses Dokument für öffentliche oder kommerzielle Zwecke vervielfältigen, öffentlich ausstellen, aufführen, vertreiben oder anderweitig nutzen.

Mit der Verwendung dieses Dokuments erkennen Sie die Nutzungsbedingungen an.

gesis
Leibniz-Institut
für Sozialwissenschaften

Terms of use:

This document is made available under the "PEER Licence Agreement". For more Information regarding the PEER-project see: <http://www.peerproject.eu>. This document is solely intended for your personal, non-commercial use. All of the copies of this documents must retain all copyright information and other information regarding legal protection. You are not allowed to alter this document in any way, to copy it for public or commercial purposes, to exhibit the document in public, to perform, distribute or otherwise use the document in public.

By using this particular document, you accept the above-stated conditions of use.

Mitglied der

Leibniz-Gemeinschaft

Persons with acquired profound hearing loss (APHL): how do they and their families adapt to the challenge?

Richard Hallam, Paul Ashton,
Katerina Sherbourne and Lorraine Gailey
*University of Greenwich & LINK Centre for Deafened People, UK,
University of Greenwich & LINK Centre for Deafened People, UK,
LINK Centre for Deafened People, UK and LINK Centre for
Deafened People, UK*

ABSTRACT The study examined the impact of acquired profound hearing loss (APHL) on the relationship between the hearing impaired person and their normally hearing close family member, usually a partner, and identified the kinds of adjustment leading to maintenance or deterioration of the relationship. The participants were 25 people with APHL and 25 family members, interviewed separately in their own home. Analysis of the interview transcripts adopted a grounded theory methodology. The different levels of analysis were linked in terms of a core category based on the social construction of a committed relationship. The conceptual codes were grouped as: (a) aural impairments giving rise to the need for adjustment; (b) pragmatic adjustments to spoken communication and family activities; (c) managing the adjustments without negative consequences; (d) adjustments leading to negative interaction. The results suggest that APHL places considerable strain on relationships and increases their vulnerability to failure, consistent with previous research. They highlight the need for professional support and suggest that a systemic conceptual framework is needed that includes the public response to profound hearing impairment.

KEYWORDS *adjustment; coping; deafened; intimate relationships; psychosocial impact*

ADDRESS R. Hallam, 56, Limes Grove, London, SE13 6DE, UK. e-mail: post@rshallam.vispa.com]

ACKNOWLEDGEMENTS The study was approved by the University of Greenwich Research Ethics Committee, April, 2002.

We gratefully thank the Big Lottery Fund Research Branch for a grant to pursue this research. We also appreciate the assistance of Maria Priestly and comments on the manuscript from Roslyn Corney.

Introduction

It would be surprising if acquired profound hearing loss (APHL) did not present a severe challenge to the maintenance of close relationships with partners and close family members. People affected by APHL have formerly been able to communicate normally; but, later in life, their hearing deteriorates, gradually or suddenly, to the point that it is no longer usable for spoken communication. The condition is relatively rare – perhaps between 1 in 250 and 1 in 500 of the population (Davis, 1994) – but prevalence is difficult to estimate because functional hearing is not solely dependent on auditory thresholds. Mild to severe acquired hearing loss (AHL) is far more prevalent and its associated disabilities and handicaps have been more thoroughly investigated. People with AHL usually strive to preserve their ‘normally hearing’ identity and to function at parity with the hearing majority (Hétu et al., 1988; Hallberg, 1999). This is usually possible with the help of technical aids, although there is often a cost associated with the effort to keep up. People with APHL may get some benefit from hearing aids but their ability to portray themselves as normal communicators is severely compromised. Efficient communication may be achieved in one-to-one situations with the help of lip-reading, signing or a cochlear implant but the effects of the hearing impairment are rarely invisible. For this reason, research on AHL is only partially applicable to the situation of people with APHL who have for some time been recognized as a distinct group (e.g. Luey, 1980; Hogan, 2001).

Although there have been no systematic studies of the impact of APHL on close relationships, the evidence that exists paints a negative picture. Hogan (2001) reported that there was a break-up of a significant relationship in 18 of his sample of 38. Schlau (2004) collected qualitative data via e-mail from 24 late-deafened adults and reported that the vast majority of comments about the response of family members were negative.

There have been some surveys of people with moderate to severe hearing loss, using questionnaire and interview methods. Kerr and Cowie (1997) found that one in 10 of their respondents felt that deafness had almost destroyed their lives, although the impact on close relationships was not addressed directly. Thomas (1984) compared a mixed severity hard-of-hearing group ($N=211$) with a group whose loss exceeded 60 dB HL ($N=88$). The rate of separation or divorce was similar to population norms in the former (7/211, 3.3%) but far greater for the latter (13/88, 14.7%). A subgroup with severe hearing loss in the mixed sample (> 70 dB HL, $n = 23$) were also more likely to be separated or divorced (13% compared to 2% in the remainder of the sample). Fifty-three per cent of the severe group

reported that hearing impairment had affected their marriage as against only 24 per cent in the remainder. There was evidence of considerable strain in a sample of 27 families who were interviewed, and several respondents acknowledged that they coped only with family support.

Research on the impact of AHL on close relationships has been conducted mainly on outpatients (Stephens et al., 1995) or on people with progressive losses due to occupational noise exposure (Héту et al., 1993; Hallberg and Barrenas, 1995) or ageing (Donaldson et al., 2004). In general, this research has underlined the need for professionals to focus on the whole family to help them to adjust (Héту et al., 1993). The stresses experienced by the impaired and unimpaired members of a close relationship are somewhat different and there are considerable opportunities for misunderstanding, blame and conflict. Jones et al. (1987) found that in the 29 families they studied, 40 per cent felt that the relationship had changed negatively as a result of hearing loss. In only 4 per cent had it changed for the better.

On the basis of several qualitative studies of people with AHL, Hallberg (1999) concluded that participants coped either by controlling the social scene or by avoiding it. Hearing people were frequently neither understanding of, nor sympathetic to, any difficulties arising. Males tended to deny or minimize their disabilities in order to protect their self-image and avoid being defined as deviant. Some partners backed up this strategy; others mediated on behalf of their spouse, while another group distanced themselves from the relationship. One might expect to find similar coping patterns in people with profound hearing loss; however, their situation is more challenging and the options of ignoring and minimizing are not available to them in most situations.

The aim of the present study was to explore the ways people with APHL, and a close family member whom they had nominated, adapted to the challenge that profound hearing impairment had imposed on their relationship. The participants were interviewed separately, face-to-face, in their own homes. The interview was loosely structured but followed a pre-defined set of topics, of which a principal one was the effect on relationships. Other topics covered in the interview do not form part of this analysis. Data of a general nature were also collected by questionnaire.

Methodology

Participants

The sample consisted of 27 deafened people, 13 male and 14 female, of whom 17 had, at some time, attended a one-week residential rehabilitation course run by the LINK Centre for Deafened People, eight were recruited from respondents to a Web-based survey on APD (Hallam et al., submitted) and two were recruited through contacts at LINK. The rehabilitation programme at LINK (described in Sherbourne et al., 2002), contains a large

educational component and, while addressing the impact on family members, is not a family therapy intervention. Participants for the study volunteered after receiving full information about its nature. Two respondents were excluded – one who failed to nominate a family member and another who nominated a neighbour. In 19 cases the second informant was a spouse/partner, in six cases a parent, sibling or daughter. The latter six informants were, in nearly all cases, the closest family member of an unmarried or widowed participant. Demographic and other details of the participants with APHL are shown in Table 1.

The definition of APHL used by LINK is an inability to follow speech by using sound alone (aided or unaided). The participants recruited through the Web survey (see Hallam et al., 2003) either could not hear sounds at all or endorsed three out of four items indicating the most severe level of hearing loss, as used in a United Kingdom government survey of disabilities (Martin et al., 1988). It was not our purpose to obtain a representative sample but to include participants who could provide a wide range of experience and perspectives. However, the extensive LINK database enabled us to select participants of all ages; we also ensured that gender, ethnicity, socio-economic status and urban and rural location approximated population norms. Their demographic, medical and audiological characteristics closely mirrored the results of our Web-based survey of 95 people with APHL.

It seemed likely that participants' individual circumstances and characteristics would influence the impact of APHL but our focus was not on families taken separately. It aimed to explore *typical* stresses, modes of adjustment and patterns of interaction. One relevant individual difference variable is suddenness of onset – 13 participants had become deafened in a matter of weeks. Other variables are age, gender, employment status, the pre-existing personality of the hearing impaired person and family member,

Table 1 Characteristics of sample with APHL (N = 25)

<i>Characteristics</i>	
Gender (male:female)	11:14
Mean age: yrs (SD and range)	53.4 (13.0, 25–77)
Married: single or widowed	20:04
Separated	01
Employed	11
Cannot hear sounds at all (unaided)	16
Wears a hearing aid	12
Wears a cochlear implant	10
Use of lip-reading, very often or always	20
Recency of onset of profound hearing loss ^a	
< 1 year	05
1–5 years	10
> 5 years	09

^a1 missing datum

the previous quality of their relationship, additional life stress and other medical conditions. Although we have evidence from other analyses that these factors are important, we did not have sufficiently detailed evidence to incorporate them into our present analysis.

Research methodology

The phenomena of interest were patterns of interaction and interpersonal perceptions in real settings, and so we adopted a critical realist approach for which grounded theory seemed most suited (Strauss and Corbin, 1990; Dey, 2004). We were concerned with observable processes rather than a linguistic or discursive interpretation of the way our participants construed their relationships. Our approach to coding followed grounded theory guidelines and worked upwards from open (preliminary, descriptive) codes, to axial (conceptually connecting) codes and finally to selective codes (core categories that relate to a broader conceptual framework).

As the focus of our study was on family relationships, we did not view the adjustments as ‘belonging’ exclusively to the individual with hearing loss. The pairs of participants spoke about themselves and each other. We were interested in generic processes of adjustment rather than treating each dyad as a case study in adjustment. Strategies of adjustment with positive and negative effects were identified but, beyond a simple classification of the overall quality of the relationship (see later), we did not wish to characterize each relationship as an example of good or poor adjustment. For these reasons, we use quotations from either the person with APhL (D) or family member (F) to illustrate the categories we develop. Where there is a clear difference of perspective, based on being hearing impaired or normally hearing, we attempt to integrate the relevant categories in our general framework. We also saw no sound reason for separate analyses of married couples versus other kinds of close family relationship. All participants nominated their family member and presumably entrusted them to divulge confidential details of their relationship.

Interview process

Participants were interviewed separately at home for 60–90 minutes each. We consider it to be important that the interviewer (PA) has a long-standing moderate to severe acquired hearing loss and many years’ experience of the kinds of problems that a person with AHL may encounter. We assume that his first-hand knowledge regarding the problems of communication, his association with the LINK charity, and to a large degree, his shared experience has enhanced his credibility, facilitated empathy and eased the exploration of relevant issues. If anything, his sympathies would probably have been more with the hearing impaired person than the family member, although we had no evidence of a bias.

The interview guide listed a number of open-ended questions, beginning with a history of the development of hearing loss, help sought and the

impact it had had on social and family life. The questions were developed in consultation with staff at the LINK centre who have had long experience of working with adults with APHL. Some questions were directed to the relationship but the interview was kept conversational in tone to allow participants to enlarge freely on their feelings. Questions were available in written form but this was rarely needed. The interviews were recorded on a digital sound recorder and the files e-mailed to a transcriber who produced a typed transcript that was then e-mailed back to the two main researchers. Transcripts could be compared to the original sound recording where necessary.

Participants were at different stages in adapting to their changed circumstances. Some participants referred back to an earlier critical period, after which there was a gradual coming to terms with their deafness. This was especially true of participants who had received a cochlear implant, the effects of which were invariably beneficial. Other participants were in the midst of a critical phase of adjustment and, in one case, in the process of a marital separation.

Process of analysis

The transcripts were entered as documents into the NVivo software package (Richards, 1999). Coding was discussed in meetings between the first author and the interviewer in order to achieve a consensual interpretation of interview material. As the open codes were developed, on an interview by interview basis, all of them were retained for potential application to the next transcript. Aspects of the relationship emerged as one of the most prominent themes. As the analysis was ongoing, the number of codes expanded as the analysis progressed. Each line of the transcribed data was examined; open coding avoided conceptual interpretation and aimed to remain close in meaning to the words used by participants. Very few new codes were added towards the end of the analysis and so an acceptable degree of saturation seemed to have been achieved. When all transcripts had been coded, the open codes were compared, contrasted, refined and reduced in number through a process of re-reading of transcripts and discussion within the wider research team.

In order to make the analysis more manageable, the open codes relating to aspects of the relationship were separated from other themes such as events surrounding onset of APD, professional help received, response of friends and the general public, communication techniques and change in perception of self, habits or lifestyle. These other themes were subsequently analysed separately.

Conceptual coding

There were initially over 120 open codes for aspects of the relationship but when all transcripts had been coded, these were reduced in number. In a conceptual level of analysis, the relationship between the open codes

was subjected to axial coding, informed by criteria of internal consistency, completeness and a theoretical interpretation that began to emerge from the analysis. A core category was also proposed (see below). Our general conceptual model will now be presented (see Figure 1) in order to prepare the reader for a more detailed presentation of the findings.

We were aware that concepts of stress and coping had been applied to similar data (e.g. Jones et al., 1987). These authors conceptualized adjustment from the point of view of the hearing impaired individual, that is, as changes in belief, behaviour or lifestyle designed to preserve the perception of control over normal functioning. We focused more on the family system as seen by pairs of family members. Adjustments were therefore seen as mutual, though not necessarily as complementary. The open codes were interpreted as reflecting attempts to stabilize the relationship or as adjustments that became a source of further stress. It is clearly extremely difficult to attribute causality to specific elements in a family system. It is our conviction that problems of communication (and their social consequences) occasioned by APHL made a significant contribution to changes in family relationships but these problems must be viewed as being in dynamic causal interaction with other factors. In our model, we have emphasized the role of social processes that establish the ground rules and motivation for individuals to maintain their commitment to each other and strive to make adjustments to an imposed difficulty.

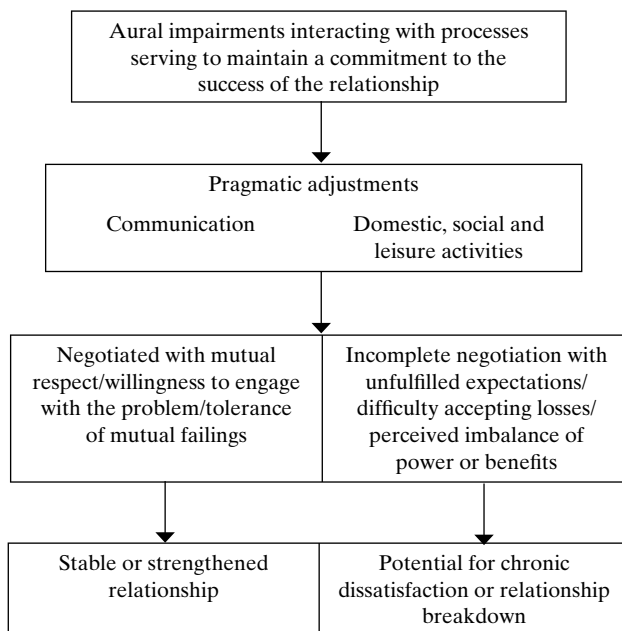


Figure 1 Conceptual model of the relationship consequences of aural impairments

There was insufficient evidence to describe the unique aspects of interactions within a family as this had been an incidental focus among others in the interview. However, when the analysis was complete, the transcripts of pairs of married participants were read in conjunction in order to make an informed judgement as to whether the relationship was 'stable' or showing signs of significant conflict or interpersonal stress. This enabled us to make some approximate comparisons with previously published quantitative data.

Categories were developed to describe different kinds of adjustment outcome, positive or negative. These outcomes were solutions to shared problems and do not refer to overall adjustment of the individual or family. The core category informing our concept of adjustment was the social construction of a committed relationship, that is, the generally accepted expectations of the duties, obligations and benefits to the partners of such a relationship, and the implicit norms governing behaviour within it. This core category enabled us to integrate the findings but, as a theoretical construct, evidence for it was indirect. A sense of commitment to a relationship is, of course, compatible with open disagreement and less obvious forms of dissatisfaction. A relationship may be committed without necessarily illustrating effective mutual adjustments. We have interpreted many of the interactions between our informants as attempts to preserve aspects of a committed relationship or to compensate for factors that threaten it. In a few cases, the person with APhL and their close family seem to have formed a new commitment on the basis of a changed lifestyle and altered values.

Mutual positive adjustment was generally reflected in shared coping strategies such as an agreement to avoid socializing in certain group situations. Strategies of this kind may have had short-term positive benefits but less fortunate consequences in the longer term. The benefits of avoidance depended on the nature of the relationship, and *any* significant degree of social avoidance could have produced a negative outcome for certain couples. Individual outcomes appear to have resulted from a mismatch or unfortunate interaction between the adjustments that each person made. Sources of stress also arose as an *indirect* consequence of the hearing impaired person's auditory limitations, especially restrictions on leisure activities, loss of social status or unemployment.

Illustration of the model

In what follows, pairs of participants are assigned the same number and identified as D (deafened) or F (family member) e.g. 10D or 10F. A series of dots indicates that part of an excerpt has been omitted. Sentences in italics are spoken by the interviewer.

Auditory impairments

The analysis of these impairments was based on references to aural perception and they are seen as prompting the adjustments that participants employed. They are familiar from previous literature (Thomas, 1984; Jones et al., 1987; Hallberg and Carlsson, 1993; Morgan-Jones, 2001) and will not be illustrated in detail. They are: (1) Quality of one-to-one communication is reduced as a result of a loss of speed and accuracy of verbal exchanges, in turn leading to a loss of spontaneity. (2) Ditto in group situations, impinging especially on family gatherings and social/leisure activities. (3) Poor voice modulation, especially in public places, leading to embarrassment, or giving the impression of an inappropriate emotional tone. (4) Failure to respond to everyday auditory signals, with consequences such as increased vulnerability to danger, substitution of a signal in a different sensory modality or reliance on others. (5) Intolerance of background sounds which are experienced as unpleasant or as interfering with spoken communication. (6) Inability to hear audio-visual equipment (e.g. TV) at normal volumes, with consequences for shared viewing and use of captioned material. (7) Altered experience of sound in general (e.g. distortion) and a negative effect of silence (absence of sound). (8) Finally, the effort of spoken communication, miscommunication and reduced social participation was interpreted as giving rise to negative emotional states such as irritability, tiredness, frustration or depression. The following quotations illustrate some of the impairments (it should be noted that we have to infer impairments from quotations that are, naturally enough, mainly about their psychosocial effects):

.... it is receding at speed, the whole quality of our interactions were being stripped away and I was fearful that I couldn't communicate with him ...(3F)

... I was finding groups of friends very hard by that point, I was tending very, very much to want to talk to people one at a time and meet people one at a time. (7D)

... she has an assertive voice and quite ordinary things are said which, by the tone of them, makes them sound offensive. (6F)

... so the loud telly, I found very, very stressful ... (7F)

Pragmatic adjustments designed to deal with impairments

These were coded as adjustments to (1) spoken communication and (2) domestic, social and leisure activities. They can be regarded as practical manoeuvres designed to facilitate the business of daily life, to speed up spoken communication or reduce the need for it. The impact of these adjustments on relationships was not necessarily either good or bad; they have the potential to be perceived positively, as signals of support, or negatively, as a sign of personal inadequacy or negative social evaluation.

Adjustments to communication A common adjustment is simply for D to exclude him/herself or be excluded from conversations that would otherwise be effortful. A modified form of this is for F to give D edited messages that would take too long to repeat fully. This adjustment impacts especially on initiating conversation, sharing gossip or partaking in social gatherings: 'So once you have spoken to someone for half an hour, you don't really repeat everything, so he probably gets frustrated that we just give him a little summary ...' (24F).

F can compensate for the tendency for D to be excluded by making sure that D is included in a conversation or informed of its content, although this is not always successful:

Sometimes, depending on the situation, if it is important then I will sort of stop the person and say, 'oh, I am not sure if he has understood, just check with him' and sometimes he just feels too polite to just ask. (24F)

So then I try and explain, by which time the moment has gone, and that makes him feel even worse. But you don't want him to feel left out so that is quite difficult. (23F)

D can compensate for missing out on spoken communication by exerting greater control over a conversation or by generally taking charge. The following quotation illustrates how normal turn-taking is superseded: 'I don't think I talked about it to R. Although I would *tell* him about it!' (2D). In this extract, D explains why she is regarded as bossy:

Bossy towards who?

Everybody, I have to be in control of things just so I know what is going on. (14D)

Instead of communicating directly, D may ask F or others to mediate in order to make a statement, convey a message, use the telephone, listen out for a signal or repeat what has been said. While this can be a helpful adjustment in certain circumstances, it diminishes D's sense of agency and, in some cases, privacy: '... and the lost privacy of going to a doctor and having to take me with him' (2F). It also has the potential for miscommunication: '... I had to take messages and this was another point of friction' (6F).

D sometimes relied on children as mediators and felt this was wrong: 'I probably did say to him "can you keep an eye on the baby" "can you tell me if the baby is crying", you know, he was eight then and he's too young really' (1D). If D fails to hear, F may direct D's attention by means of touch. Often this is innocuous but it can be experienced as intrusive: 'I try not to shout and I try not to prod ... but occasionally ... it does turn into a prod and I hate it when I do that ...' (20F).

Adjustments to domestic, social and leisure activities For routine tasks that require conversation, such as shopping, F may take them over as a

matter of practical convenience. D may later find that they would prefer to resume these tasks: 'Shopping, my husband is mostly doing ... he would volunteer to do it on a Saturday, although he never used to. Although I'm trying to wrestle it back now ...' (1D).

Social and leisure activities may be curtailed because they are no longer pleasurable: 'We stopped going out and I get quite worked up about the idea, if they were to invite us I don't want to go ... it is not pleasure' (3F). F may lose out, too, on joint activities that have been given up: '... we used to like going to the cinema, a concert, R loves music' (6D). D and F may modify their activities without giving them up altogether: '... what I prefer now is, well, four people maximum ... we used to go for a meal, eight of us, and then I said I wasn't going to go because I just couldn't cope with it' (11D).

Managing the adjustments without negative consequences for the relationship

As noted earlier, adjustments need not become a source of contention. For example, F may give support, as required, as part of the commitment to the relationship: 'I have a disability myself and I rely on him or other people to do things for me ...we sort of do things for each other, sort of thing ...' (24F). Partners may be receptive to learning how best to adapt:

It's not so much the communication, it's more the strategies she's taught me like when we sit in the kitchen, I sit so that I'm facing the light so she can see my face and I just know to do that, but then she is a good teacher. (11F)

If difficulties arise, these are just treated as a matter of course, in an atmosphere of mutual acceptance: 'J sometimes gets a bit frustrated with me but she does not mean it, it is just a normal thing' (13D). F may want to compensate but is careful not to overstep the mark and provide unwanted support: 'I think he expects the support. I let it go as far as I can without intervening or interrupting ...' (23F).

F may be careful to preserve D's sense of autonomy: '... she is the kind of person who says she knows what she can and she can't hear, and if she can't hear, she is quite happy to pass it over to someone who can' (17F). F has to exercise judgement in not being over-supportive and may have to 'push' D to be more autonomous: 'I have made him go out and do that ... But you have got to know when to do it and when the time is' (10F). F may strive to maintain D's autonomy and feel frustrated if this is not possible: '... in a way we have taken over, he does try, he does want to stay in control and manage but he can't. That is frustrating' (18F). The adjustments that F has to make often require extra effort but D acknowledges this as a potential burden on F: 'I just did not think it was very fair to keep asking him what they were saying. I couldn't keep up with it so I just stopped going' (20D).

F may acknowledge their own deficiencies but this does not seem to imply self-condemnation or resentment of D (an interpretation supported by the surrounding text):

I don't know. I would be a long way from being perfect and being the most sympathetic or empathetic that I think I could have been. (1F)

I am probably the world's worst. I will just treat her as though she can hear me ... (17F)

F makes allowances for D when failures of communication occur: 'Yes, well this is where the breakdown of communication comes, isn't it? Through no fault of hers' (6F). F may have to sacrifice some of their own enjoyments but this seems to be done as part of the give and take of a committed relationship. For example, F reduced his sporting activities: 'So I cut them down because it would mean leaving her too often and apart from that I don't want to play that much now' (8F). F may 'take charge' of a situation but there is an implication that this is exceptional and temporary:

I said to him not long ago that I felt more like his mother than his wife for a while ... I stayed as strong as possible because I thought somebody has got to be strong in the partnership. (10F)

I think sometimes Mum probably prefers me to stand up, rather than her have to say 'I'm deaf, I can't hear you.' Especially, over and over again to close family members, I will have a go at them instead. (21F)

In some instances, the adjustments that F has to make give them greater self-confidence: '... and it has made me a much stronger person, much stronger, I didn't know I had this much strength in me' (10F).

Adjustments leading to negative interactions or vicious circles

Signs of manifest interpersonal stress were evident in more than half the transcripts. The manner in which participants had adjusted to impaired communication seems to have led to increasing strain and, in one couple, breakdown of the relationship. An uneasy compromise prevailed in some cases although this may have existed prior to D losing their hearing. In line with our core category, we interpret manifest stress as originating in:

- (1) A perception by D or F that the other 'ought to do better' because he/she has departed from their (perhaps implicit) model of expected behaviour. This perception may create a sense of inequity in the relationship overall.
- (2) A loss of relationship quality, experienced as frustrating or unfair.
- (3) Negative public perceptions of D that in turn impact negatively on F.

Departure from expected behaviour or attitude F may feel that D is either simply not trying hard enough to compensate for their disability or ought just to accept it: 'Uhm ... you shouldn't dwell on these things, you should just get on with living and you do the things you can do and feel that maybe

that you are better off than a lot of other people' (6F). F may perceive that D expects too much of them and sets limits on how much they are willing to adjust: 'I intended to carry on leading what had become a normal life. Although it wasn't going to be normal any more, there was no reason why you should suddenly have your whole world collapse about you ...' (4F).

F may feel they are giving support and it is not being appreciated: 'Yes, she does not look for support but she certainly needs support and I give her support. Now, she might argue with that and say I don't support her, I don't know what she would say about that' (8F). F may try to be accommodating but then feel that they are falling short of D's expectations:

Whenever I came off the phone invariably she would say 'oh, did you ask them so and so' and you know, 'shit', I have gone through all this and that is the one question she wanted to ask and I did not ask them and that seemed to happen repeatedly. (6F)

Conversely, D may think that F should be more supportive or may feel that F has a grudging attitude. The implication from the context of the first quotation is that her husband should have been more involved in helping her to adjust:

... my husband, I felt that it didn't affect him very much. He wasn't unkind or unhelpful, he just carried on as normal. (20D).

... having to wait for him to make the phone call. And not that I couldn't do it myself or that he had to do it, but his reluctance to do it, you know, 'oh, do I have to?' (2D)

D may feel that F should be more understanding about being asked to make specific adjustments (in this instance, reported by F): '... I think J found that annoying because he was finding it so difficult to control his volume, so he found it quite annoying to be asked' (7F). D may criticize F's hearing tactics with the implication that he/she should try harder:

I was aware of it causing tension, but not of my point of view. It was they that weren't doing the communicating (*laughs*) ... I felt very much it was me having to do all the work. Giving them deaf awareness all the time. (2D)

F may feel that D is not making an effort to communicate:

... as soon as I get in, M is able to unload the story of her day, what she has been doing whereas I am trapped in as much as I couldn't go into detail and tell M about my day. It is sometimes just a few sentences so, whereas she is able to communicate to the relationship, I am not. (14F)

Even when pragmatic adjustments have been made jointly, D may still feel disadvantaged and appear to implicate F in their disappointment: 'I definitely feel as if I have lost my independence because you always seem to need somebody with you and doing things for you' (6D).

D's hearing loss may bring about changes to the relationship that lead to a reassessment of its reciprocal benefits and/or distribution of power. This may be experienced as an inequality that is resented:

... I think she probably resents me a little bit because I am still able to do things that we have always done and she can't and she sees me now as the one that is in control. (8F)

It is very hard to live with the fact that I did not have time on my own. (10F).

F may feel that D has somehow emerged with greater benefit from the new situation:

... it seems really strange to say it but it seems that everything positive has happened to B and all the negative comes down on me but that is the way you view life I suppose, and what happens to you. (14F)

F's sense of being the person on whom D depends may be experienced as a burden: 'I could never leave him because he is so dependent. He doesn't recognize it, he would never say or even think it, but I think he is ... very dependent on our relationship ...' (9F).

Loss of quality in the relationship One cause of a loss of quality is a failure to repair a breakdown of conversation in a satisfactory manner:

I can't make him understand, well I say, it doesn't matter, forget it. He says, it does matter, so I sort of have to try and understand what I mean, otherwise he gets all ..., and his heart starts beating faster and I don't want to get his heart up. (13F)

D or F may also miss the spontaneity and depth of one-to-one conversation and companionship generally:

I have pretty well missed regular normal conversations with them and it has been rather tedious both from their point of view and from mine. (3D)

It is very stressful, I cannot, a part of our relationship in a way has died in ..., and I might weep here (*obviously upset and tape paused*). (3F)

One function of a close relationship is to talk about stresses that originate outside it (i.e. a mutual 'offloading of emotion'). Understandably, D or F might feel a need for emotional release but the usual give-and-take exchange seems to break down:

... this problem never seemed to gravitate outside the front door and it was all directed at me. (6F)

She doesn't like being excluded and sometimes that can be upsetting for her and for me. I mean I get upset by it but then I get the double whammy because she gets upset with me as well. (11F)

D or F may go outside the relationship to unburden themselves: '... she has got a couple of friends, one of them is my cousin who she talks to and really

tells her feelings to whereas she knows it would probably upset me' (14F). The opportunity for shared intimacy in social situations is also affected: 'Often left the evening with feeling annoyed, angry even, rather than having said "oh that was a good evening", just because she couldn't follow' (11F).

Public perceptions of the deafened person D and/or F may feel upset when D is perceived differently because of their deafness:

Annoyance when we are out socializing and I am stood at the side of my husband and people look past me to him, and don't include me. Even if they are asking me something, they ask J as a third party to ask me and it is like you become a different person. (8D).

S may perceive others' response to D as personally humiliating: 'And to be faced across the table with two people who are in hysterics over W confirming what he thinks he has heard, I couldn't handle it' (3F).

F may begin to perceive D differently as a result of their changed social persona:

He hasn't been able to show his sense of humour, and within the group. It's probably affected us in ways that I'm not really aware of because I don't know how it would be different otherwise, but I'm sure that has had an effect on the way I perceive him socially. (7F)

D may realize that they are embarrassing F. In the following situation, in a restaurant, D had complained about the behaviour of some other diners: 'C said I positively shouted at her and we could all have hid under the table. It doesn't sound like shouting to me but they went which was good' (11D).

Perceived threat to the relationship

Several participants intimated that their relationship had been placed in jeopardy by the challenge of deafness. One couple was in the process of separating and problems caused by deafness appeared to be important contributing factors. Another volunteer for the research, who later withdrew, said that her own hearing difficulties had led to the ending of her marriage. The following quotations illustrate participants' worries:

He always looks shocked when I talk about the threat to our marriage, it is more fundamental and I told him it is a threat to our relationship and I was fearful ... (3F)

... it was quite distressing and it has led to some enormous strains on the relationship which I think we have patched up ... I hope we have patched up anyway. (6F)

Discussion

The decision to interview family members as well as the person with APHL seems to have resulted in an even-handed representation of the difficulties

that couples and families were facing. We did not encounter much blame or acrimony – and this was true also of the couple who were in the process of separating. Family members provided a considerable amount of information about the impact on the person with the hearing impairment, as reflected in the number of quotations they provide. For many, it was their first opportunity to voice their point of view as none of the participants had ever received any counselling together. (It should be noted that the LINK course provided an opportunity for this but not all family members had attended and many of the sessions were in a group format.) The decision to interview participants separately meant that feelings were expressed that could not have been expressed in a joint interview. However, in view of the fact that some participants reported humiliating and other negative experiences in their dealings with professionals or the general public, it seems likely that some views were held back.

The results indicate that APhL can affect a family in complex and subtle ways. Evidence of interpersonal stress was found in at least half of the married participants, a proportion close to the 53 per cent of people with a severe hearing loss who reported that deafness had affected their marriage (Thomas, 1984: 95). Although not emphasized here, the contribution of additional medical problems (especially tinnitus and imbalance) and the stress associated with obtaining diagnostic information and appropriate medical and rehabilitation support should not be underestimated.

The negative impact of APhL on many of the families replicates the findings of previous research. It would be inappropriate to designate partners as ‘carers’ but APhL imposes a considerable burden of extra effort. Old habits of communication have to be changed and family members often admitted their own deficiencies in this respect. Domestic, social and leisure activities may have to be modified or curtailed. All this presupposes a willingness on the part of the family to engage with the problem. Family members, including children, may have to take over domestic duties or act as intermediaries in a variety of situations. As reported by Jones et al. (1987), the presence of problems in communication may subvert prevailing power relationships as the person with APhL becomes more assertive or more dependent.

Our sample was not designed to be representative of all people with APhL although we assume that our model describes the generic pathways that lead to maintenance or breakdown of relationships. We have not taken account of stage of adjustment to hearing loss, stage in the life cycle, effect on employment or the benefits of cochlear implantation, all of which are likely to be important moderating influences that deserve further study. However, from the limited information we obtained in interviews, none of these factors would appear to be critical to the relationship, acting independently of other influences. We are also unclear why a large number of potential volunteers declined to participate. We suspect that many families did not want their relationships put under the microscope. In one case,

a volunteer withdrew after her relationship broke down. It seems likely that a random sample of people with APhL would evidence more signs of stress or dissatisfaction. Many of our participants had responded favourably to help offered earlier by LINK and were willing to devote time and effort to our research.

The adjustments made by our participants are similar to ones described in research on AHL (e.g. Thomas, 1984: 134–45; Hallberg, 1999). The person with hearing impairment tended either to be excluded from conversation or, less frequently, to take control of it. For many families in our study, the adjustments were made in a spirit of give-and-take and unquestioned commitment. In managing the necessary changes, many families negotiated with respect and consideration. This involved a mutual acknowledgement of the burden, each party accepting and forgiving an inevitable falling short of expectations and the need to make allowances, a respect for the dignity, autonomy and capabilities of the person who needs support and an obligation on the latter to make reasonable efforts. Participants in the study were well aware of the potential to do too much, to neglect a person's need for independence or to fall prey to a loss of respect.

However, for some families, APhL sets in train a negative pattern of interaction. Whether or not this happens may depend on the prior state of the relationship and the personalities involved. Participants certainly expressed expectations of each other that, in some cases, remained unfulfilled, leading to a sense of loss, frustration or resentment. It cannot help matters that problems of communication are likely to obstruct the means by which any problem usually gets solved, that is, through negotiation. Profound hearing loss hinders the spontaneous expression of mutual regard and reduces the opportunity for positive shared experiences. Some participants also mentioned their frustration at not being able to 'offload' about the normal stresses of the day.

The strain on the family includes a public response to APhL that is often deeply prejudiced or, at best, uncomprehending. An analysis of this aspect of the data is currently in progress but participants spoke of family members or longstanding friends who could not really be bothered to alter their usual mode of communication. The person with APhL was sometimes regarded as stupid or was simply bypassed in conversation. If they were not able to deal effectively with this treatment, family members often felt obliged to intervene. In these circumstances, the family was precipitated into a joint defensive posture.

In terms of our core category – the prevailing social construction of a committed relationship and its rights, obligations and benefits – we infer that a substantial proportion of participants felt short-changed in their opportunities for intimacy and shared social enjoyments. Participants expressed a variety of mutual criticisms such as a lack of support or understanding, and poor hearing tactics. These complaints must be viewed in a social context of significant disadvantages for people with a profound

hearing loss in the job market (if not loss of employment), and little public recognition of the needs of people with APHL (LINK Centre, 2005).

Authors such as Schlau (2004) have rightly argued that there are stages of adjustment to APHL but her view that it is desirable for the person concerned to accept a new identity as a 'deafened person' who goes through a defining moment of acceptance, learns to sign, finds deaf friends and accepts deaf ways, is unlikely to be generally accepted. In fact, only one-third of her respondents had managed to achieve this and the remainder were described as 'struggling' or 'resigned'. Our participants did not seem to place such an emphasis on identity, which might reflect differences between a US and UK cultural context. Our participants depended primarily on lip-reading and only one signed regularly. Adopting the identity of person who is deaf is not a preferred way forward in the UK where the deaf community tends to exclude most people with APHL.

A focus on individual adjustment also neglects to consider how the family of the affected person fits into this developmental picture. As Hétu et al. (1993: 375) have rightly stressed, professionals must attend to the interactive dimension of the difficulties and of the coping process. The impact on family members often seemed greater than on the person with hearing loss, him or herself. Given the variety of individual circumstances, it would be difficult to define an ideal outcome of adjustment applicable to all. In a similar vein, Jones et al. (1987: 215) paint a complex and non-prescriptive picture of family adjustment in the hard-of-hearing community.

As noted earlier, we were unable to do sufficient justice to variables such as age, gender, the prior quality of the relationship, personality characteristics and having to cope with other medical conditions or sensory impairments. We are currently analysing our data to investigate the influence of gender, which has been found to be an important variable (Stephens et al., 1995; Wallhagen et al., 2004). Like other qualitative researchers in this field, we have found it necessary to locate these variables within higher order constructs. Hallberg et al. (2000) derived a core concept of 'finding flow', with the implication that individuals enter a 'positive circle' if they do or a 'negative circle' if they do not. This formulation hints at a dynamic system but in fact their concepts refer to individual dispositions related to Antonowsky's (1987) concept of sense of coherence. These authors were investigating coping with everyday life situations, such as work, and the dispositions they describe may or may not be suited to maintaining flow in family relationships.

Our model and the findings on which it is based are entirely consistent with the views of Hétu et al. (1993) working with older people with AHL. These authors stress that counselling should focus equally on the needs of the hearing impaired person and their partner. The aim is to facilitate communication about conflicting views, roles, needs and costs, so that misunderstandings and disagreements can be resolved by negotiation. Hétu and colleagues recommend that this can be done in groups. Our research

suggests that taken-for-granted assumptions about the grounds of commitment to a relationship can be put into question by the consequences of APHL. When a relationship is seriously threatened, couples counselling is indicated. In the acute stage of onset of hearing loss, especially if this is sudden, counselling may have to focus on managing a crisis and extreme emotional responses. The most appropriate intervention would depend on the individual case and the stage of adjustment.

References

- Antonowsky, A. (1987). *Unravelling the mystery of health: How people manage stress and stay well*. San Francisco, CA: Jossey-Bass.
- Davis, A. (1994). *Hearing in adults*. London: Whurr.
- Dey, I. (2004). Grounded theory. In C. Seale, G. Gobo, J.F. Gubrium and D. Silverman (Eds.), *Qualitative research practice*, pp. 80–93. London: SAGE.
- Donaldson, N., Worrall, L. and Hickson, L. (2004). Older people with hearing impairment: A literature review of the spouse's perspective. *Australian and New Zealand Journal of Audiology*, 26(1), 30–9.
- Hallam, R.S., Ashton, P., Sherbourne, K. and Gailey, L. (2006). Acquired Profound Hearing Loss: Mental health and other characteristics of a large sample. *International Journal of Audiology*, 45(12), 715–23.
- Hallberg, L.R.-M. (1999). Hearing impairment, coping, and consequences on family life. *Journal of the Academy of Rehabilitative Audiology*, 32, 45–59.
- Hallberg, L.R.-M. and Barrenas, M.L. (1995). Coping with noise-induced hearing loss: Experience from the perspective of male victims. *British Journal of Audiology*, 29(2), 219–30.
- Hallberg, L.R.-M. and Carlsson, S.G. (1993). A qualitative study of situations turning a hearing disability into a handicap. *Disability, Handicap & Society*, 8(1), 71–86.
- Hallberg, L.R.-M., Passe, U. and Ringdahl, A. (2000). Coping with post-lingual severe profound hearing impairment: A grounded theory study. *British Journal of Audiology*, 34(1), 1–9.
- Hétu, R., Jones, L. and Getty, L. (1993). The impact of acquired hearing loss on intimate relationships: Implications for rehabilitation. *Audiology*, 32(3), 363–81.
- Hétu, R., Riverin, L., Lalande, N., Getty, L. and St-Cyr, C. (1988). Qualitative analysis of the handicap associated with occupational hearing loss. *British Journal of Audiology*, 22(3), 251–64.
- Hogan, A. (2001). *Hearing rehabilitation for deafened adults: A psychosocial approach*. London: Whurr.
- Jones, L., Kyle, J.G. and Wood, P. (1987). *Words apart: Losing your hearing as an adult*. London: Tavistock.
- Kerr, P.C. and Cowie, R.I. (1997). Acquired deafness: A multidimensional experience. *British Journal of Audiology*, 31(2), 177–8.
- LINK Centre. (2005). *Hidden lives: The psychological and social impact of becoming deafened in adult life*. Eastbourne, UK: LINK centre report.
- Luey, H.S. (1980). Between worlds: The problems of deafened adults. *Social Work in Health Care*, 5(3), 253–65.
- Martin, J., Meltzer, H. and Elliott, D. (1988). *The prevalence of disability amongst adults: OPCS surveys of disability in Great Britain Report 1*. London: Her Majesty's Stationery Office.

- Morgan-Jones, R.A. (2001). *Hearing differently: The impact of hearing impairment on family life*. London: Whurr.
- Richards, L. (1999). *Using NVivo in qualitative research*. Bundoora, Australia: Qualitative Solutions and Research Pty.
- Schlau, J. (2004). 'I did not die, I just can't hear': A grounded theory study of acquired deafness. Unpublished PhD dissertation, Long Island, NY: Hofstra University.
- Sherbourne, K.S., White, L. and Fortnum, H. (2002). Intensive rehabilitation programmes for deafened men and women: An evaluation study. *International Journal of Audiology*, 41(4), 195–201.
- Stephens, D., France, L. and Lormore, K. (1995). Effects of hearing impairment on the patient's family and friends. *Acta Otolaryngologica*, 115(2), 165–7.
- Strauss, A. and Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Los Angeles, CA: SAGE.
- Thomas, A.J. (1984). *Acquired hearing loss: Psychological and social implications*. Orlando, FL: Academic Press.
- Wallhagen, M.J., Strawbridge, W.J., Shema, S.J. and Kaplan, G.A. (2004). Impact of self-assessed hearing loss on a spouse: A longitudinal analysis of couples. *Journal of Gerontology, B, Psychology and Social Science*, 59B(3), S190–S196.

Author biographies

RICHARD HALLAM is a researcher and clinical psychologist. He worked at the Royal National Throat Nose and Ear Hospital, London, for eight years and has published widely on psychological aspects of audiological medicine. He is currently Visiting Professor of Clinical Psychology at the University of Greenwich and also works in the UK National Health Service.

PAUL ASHTON trained as an economist and for 14 years conducted academic research, mainly at Liverpool University's Macroeconomic Research Group. As someone who has a hearing loss, he has experienced at first hand some of the social and psychological effects investigated in this study.

KATERINA SHERBOURNE trained as a medical doctor and has an MSc in social research. She has worked at the LINK Centre for Deafened People for 11 years and has published a formal evaluation of the efficacy of its rehabilitation programmes.

LORRAINE GAILEY completed a PhD in the psychology of speechreading in 1981 and qualified as a speech and language therapist with a special interest in the rehabilitation of adults with acquired deafness. Since 1991, she has been Chief Executive of the Link Centre for Deafened People in Eastbourne, East Sussex.